



Questions?
Contact Name
Contact Email
Contact Phone

ADULT IN-PERSON SURVEY (IPS) 2017-18

Previously known as the Adult Consumer Survey (ACS)

SC-1 Survey Code: _____

Note: This code should be provided by the state project coordinator and is for data analysis purposes only. A unique survey code should be assigned to each person. Do NOT use a number that could possibly identify the person (for example, *do not* use social security numbers).

SC-3 Region or County (if applicable): _____

SC-4 Language in Which Survey was Conducted:

- ☐ 1. English
- ☐ 2. Spanish
- ☐ 3. Other _____

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ADULT IN-PERSON SURVEY (IPS) 2017-18

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Before you start...

The following are instructions for completing the five parts of this survey.

- **Pre-Survey**. This information may be useful for scheduling and conducting the face-to-face surveys. It is not analyzed by HSRI and cannot be downloaded from the Online Data Entry Survey Application (ODESA).
- **Background Information**. This information *will* be analyzed by HSRI and must be collected for all individuals surveyed. Most states collect this information from case manager or system records; however, some states use surveyors to collect some of this information directly from the individual, guardian/conservator, or family member. The state will specify which elements need to be obtained directly by the surveyor.
- **Section I**. These questions may only be answered by face-to-face meetings with the person receiving services and supports. These are subjective, satisfaction-related questions that may not be answered by anyone else.
- **Section II**. These questions may be answered by the individual or someone who knows the person well (proxy respondent)—such as a family member, friend, staff person, guardian, or advocate. Service coordinators or case managers are not allowed to respond to questions in this section. If the individual is answering, the questions need to be asked face-to-face. If a proxy respondent answers, questions need to be asked face-to-face if at all possible. Questions for proxy respondents may be asked over the phone only when a face-to-face meeting is not possible.
- **Surveyor Feedback Sheet**. This is the last page of the survey. Please fill out one sheet for each survey you complete.



Pre-Survey

ADVICE TO STATES. The Pre-Survey is intended to provide surveyors with the information they need to schedule and conduct the face-to-face surveys. The state should review this form and decide what information will be provided to surveyors in advance (e.g., name, phone number, communication needs, etc.), how the information will be gathered (e.g., service coordinators, databases, surveyors etc.), and the administrative procedures (including informed consent) that must be followed when arranging the face-to-face surveys.

None of the Pre-Survey information is submitted to HSRI. **Actual procedures for using the Pre-Survey Form should be determined by the state's NCI coordinator and communicated to surveyors during training.** These procedures should also be communicated to HSRI.

ADVICE TO SURVEYORS. Please fill out and review as many of the Pre-Survey items as possible before starting the face-to-face survey. Experience shows that using familiar names and terms helps the respondent understand the questions being asked and facilitates the survey process. You can also use this form to fill in blanks in Sections I and II of the survey: look for items marked with a 🔔 symbol. Doing this prior to the face-to-face survey helps the conversation flow more smoothly.

Additional instructions regarding your state's specific administrative procedures:

The Supporter Communication questions must be asked of the Support Worker who knows the individual best. It is recommended to ask these questions over the phone and schedule the interview when the Support Worker will be present.

A. Person(s) completing this form

Name(s):

Date: ____/____/____

B. Person to be surveyed

First and Last Name

Gender: ☐ 1. Male ☐ 2. Female ☐ 3. Other

Age

Phone

Email

Address Line 1:

Address Line 2:

City

State

Zip

C. Legal guardian/conservator information, if applicable

Guardian's/Conservator's Name

Relationship to Individual

Phone

Email

Street Address

City

State

Zip

D. Approval requirements and procedures

ADVICE TO STATES. Each state will follow its own specific requirements for getting the individual's consent or agreement to participate.

ADVICE TO SURVEYORS. At a minimum, you need to obtain verbal agreement from the individual (or his/her legal guardian/conservator, if applicable) before the face-to-face survey takes place.

Note. The agreement/approval question at the beginning of Section I must be answered.

PS-1. Contact

Who should the surveyor call to arrange a face-to-face survey with this person (individual, parent/guardian/conservator, day or residential program staff, etc.)?

Name _____

Relationship to Individual _____

Phone #1: _____

Phone #2: _____

Email _____

Parent Contact Information _____

Meeting Companion: Should a caregiver be present? We would like to conduct the face-to-face survey with the individual alone, when appropriate. However, some individuals may feel uncomfortable with strangers and some individuals may have medical, behavioral, or other reasons for supervision or support from designated caregivers.

Do you recommend that a caregiver be present while this person is surveyed? ☐ 2. Yes ☐ 1. No

If yes, please explain:

Accommodations: Does this person need any accommodations? Examples: Communication – sign language, communication device, voice amplifier, someone familiar with the person’s communication style, interpreter if primary language is something other than English; Accessibility – transportation, space issues; Other – medical, allergies

Please explain the arrangements needed for the face-to-face survey:

CA – Supporter Communication Questions

Name of support worker: _____

How long have you supported the individual? _____

What can I do to make (individual) more comfortable during the interview (e.g., placement of materials, space between the interviewer and individual, support person in the room or not)?

How does the person best communicate (e.g., verbally, with picture cues, gestures)? _____

If the person is non-verbal, do you know how the individual responds to yes and no questions? (What is a yes? What is a no? Can you describe both)? _____

Does the individual need more time to process questions and respond?(If the person does not respond right away, does that usually mean s/he needs time to think through the question, or that s/he does not understand the question?)

How will this person let us know if s/he does not understand the question? If the (individual) does not seem to understand a question, is it better to repeat the question or rephrase it? _____

Is there anything else we should know about this person to facilitate discussion? _____

PS-2. Case Manager/Service Coordinator



What is the name and contact information of this person's case manager/service coordinator?
This should be referenced when asking **Questions 33, 34, and 69**.

Name

Telephone:

Email:

Cell Phone:

PS-3. Person who can provide information about this individual's employment



Please indicate the person (e.g., Job Coach, Case Manager) who can provide the most accurate information about this person's employment, such as hours worked and wages earned. This information is needed for Questions **BI-51- BI-54** in the Background Information Section.



Name	Relationship
Email	Phone

PS-4. Proxy Respondents

If you believe this person may be unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who know him or her well and could respond on his/her behalf. Family members, guardians/conservators, friends, and staff may respond; case managers/service coordinators *may not* respond.

Respondent 1:	Relationship
Email	Phone
Respondent 2:	Relationship
Email	Phone

PS-5. Living Arrangement



Please indicate who this person lives with.

This should be referenced when asking **Question in Section II**.

- ☐ 1. Lives alone
- ☐ 2. Lives with parent/relatives
- ☐ 3. Lives in large residential care facility
- ☐ 4. Lives in shared house or apartment
- ☐ 5. Lives with partner, spouse, and/or children

If applicable, provide first names of roommates or housemates:

PS-6. Support Staff

If there are any people who are paid to provide supports in this person's home, at work, or at their day program, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person.



This should be referenced when asking **Questions 41-43** and **Question 70**.

PS-7 Employment

If applicable, please indicate the place of work (employer or work program names) for this person's paid community job(s). A community job refers to *paid work*—either competitive or supported employment. Examples include both individual and group employment, such as a work crew or enclave. It does not include work done in a facility-based setting (e.g., sheltered workshop) or volunteer work. Use the term or abbreviation the person is most familiar with.



This should be referenced when responding to **Questions BI-43 - BI-48** in the Background Information Section, and when asking **Questions 7, 9, and 66**.

Place of work:

PS-8. Day Program or Sheltered Workshop

If applicable, please indicate whether this person attends a program or sheltered workshop during the day. Note: This does not include a paid job in the community (see PS-7). Use the term or abbreviation the person is most familiar with.

- **Day programs** for people with intellectual and developmental disabilities are typically segregated and may provide socialization, habilitation, prevocational and skills training, and social and/or recreational activities.
- **Sheltered workshops** are facility-based day programs where people with intellectual and developmental disabilities spend their days in a segregated setting to carry out specific tasks (often piece-work).



This should be referenced when asking **Questions 11 and 67**.

Day program/workshop:

PS-9. Self-Advocacy Organization



This should be referenced when asking **Question 73**.

What self-advocacy groups are active and well-known in the person's area (e.g., People First, Self-Advocates Becoming Empowered, Speaking for Ourselves)?

PS-10 Self-Directed Supports



This should be referenced when asking **Questions 81-89**.

Is this person currently using a self-directed/participant-directed supports option and using a financial management service (also called a fiscal agent, fiscal intermediary, intermediary service organization,


etc.)? These options offer individuals (and their representatives) the opportunity to manage some or all of their services. For example, they may hire and fire their own support workers and/or have control over their budget or services.

(NOTE: This person should be asked the questions in the Self-Directed Supports Module at the end of Section II.)

- ☐ 2. Yes
- ☐ 1. No

If yes, what is the term used to describe the participant-directed budget (e.g., individual budget, DDS budget, etc.)? Please note the term that would be most familiar to the person:


PS-11. Financial Management

 This should be referenced when asking **in Section II**.

If the individual uses a self-directed supports option and uses a financial management service (also called a fiscal agent, fiscal intermediary, intermediary service organization, etc.) to manage his or her services and supports budget, what is the name of that organization? Please note the term that would be most familiar to the person:

PS-12. Hiring/Managing Staff

Does this person employ his/her own staff?

 This should be referenced when asking **Question 83** in Section II.

- ☐ 2. Yes
- ☐ 1. No

When making initial call to the person to be interviewed.

Hello, I would like to speak to _____. I am with the State Council on Developmental Disabilities. We are a State agency that works with the Regional Center.

You have been selected to participate in a survey to find out your opinions of Regional Center services and your life. The survey is confidential. The answers you give us along with everyone else we interview, will be used to help the state make better decisions in providing services you need.

We are very interested to hear what you think. You are not required to participate if you don't want to. It's OK to say no. If you are interested, I would like to set up a time to meet with you. You can choose the place and time of the meeting and anyone whom you would like to be with you. It will take about an hour of your time. Can we set up a time now?

◆ END OF PRE-SURVEY FORM ◆



Background Information

This section should be completed along with the Pre-Survey Form by the appropriate agency staff member, such as a case manager/service coordinator, according to state-specific protocols. For some items, either the individual receiving services, a residential staff person, or a family member may inform the response to the questions.

IMPORTANT: Background Information (BI) items that are highlighted represent critical items for data analysis purposes. Please make every effort to provide this information so that your state's data can be fully analyzed.

Personal

BI-1. Zip Code (where person resides) _____

Please note that the zip code will not be stored. When entered into the online data entry system, it will be converted into a rural/urban designation.

BI-2. Date of Birth: (mm/yyyy) ____/____/____

BI-3. Gender

- ☐ 1. Male
- ☐ 2. Female
- ☐ 3. Other

BI-4. What is this person's race and ethnicity? Check ONE or MORE races to indicate what this person considers himself/herself to be:

- ☐ 1. American Indian or Alaska Native
- ☐ 2. Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or Other Asian)
- ☐ 3. Black or African-American
- ☐ 4. Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)
- ☐ 5. White
- ☐ 6. Hispanic/Latino (Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, or Other Spanish/Hispanic/Latino)
- ☐ 7. Other race not listed
- ☐ 99. Don't know

BI-5. Does this person have a legal appointed guardian/conservator (a person who is legally granted authority to make decisions on behalf of the individual)? Check ONE.

- ☐ 1. No, person does not have a guardian/conservator (legally competent or presumed competent) —> code BI-6 as 'Not Applicable'
- ☐ 2. Yes, limited guardianship/conservatorship (a person has authority over certain decisions, such as entering into contracts, medical procedures, etc.)
- ☐ 3. Yes, full guardianship/conservatorship
- ☐ 4. Yes, unable to distinguish between limited or full guardianship/conservatorship
- ☐ 99. Don't know

BI-6. If this person has a legal/court-appointed guardian/conservator, what is the guardian's relationship to the individual? Check ONE.

- ☐ 98. Not Applicable
- ☐ 1. Family
- ☐ 2. Friend
- ☐ 3. Public guardian/Public administrator
- ☐ 4. Financial institution (e.g., bank)
- ☐ 5. Non-profit guardianship agency
- ☐ 6. For-profit guardianship agency
- ☐ 7. Other: _____
- ☐ 99. Don't know

BI-7. Marital status. Check ONE.

- ☐ 1. Single, never married
- ☐ 2. Married
- ☐ 3. Single, married in the past
- ☐ 99. Don't know

BI-8. Is this person a parent? (This includes adult children.) Check all that apply.

- ☐ 1. No, does not have a child —> code BI-9 as "Not Applicable"
- ☐ 2. Yes, parent of a child or children under 18
- ☐ 3. Yes, parent of a child or children over 18
- ☐ 99. Don't know

BI-9. If the person has children under 18 years of age, does the child or children live with the person? Check One.

- ☐ 98. Not Applicable – no child or child is an adult
- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-10 Is this person diagnosed with an intellectual disability (ID)?

- ☐ 1. No —> code BI-11 as 'Not Applicable'
- ☐ 2. Yes
- ☐ 99. Don't know —> code BI-11 as 'ID diagnosis unknown'

BI-11. If yes, what level of ID?

- ☐ 98. Not Applicable – no ID diagnosis
- ☐ 1. Mild ID
- ☐ 2. Moderate ID
- ☐ 3. Severe ID
- ☐ 4. Profound ID
- ☐ 5. Unspecified Level of ID (Individual has been diagnosed with ID, but level of ID is unknown)
- ☐ 6. ID diagnosis unknown (only use this response if BI-10 is marked "99 Don't Know")

BI-12 What other conditions are noted in this person's record?

CHECK ONE ANSWER FOR EACH ROW. This is very important for data analysis purposes. Check "YES" if the person has the listed condition; check "No" if they do not; check "Don't Know" if information is not available.

No Yes Don't Know

- | | | | |
|-----------------------------|-----------------------------|------------------------------|--|
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Mood disorder (e.g., depression, mania, bipolar disorder, etc.) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Anxiety disorder (e.g., obsessive disorders, panic disorders, etc.) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Behavior challenges (e.g., aggression, self-injurious behavior, pica, etc.) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Psychotic disorder (e.g., schizophrenia, hallucinations, etc.) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Other mental illness/psychiatric diagnosis |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Autism spectrum disorder (e.g., autism, Asperger syndrome, pervasive developmental disorder) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Cerebral palsy (spastic quadriplegia/diplegia) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Brain injury |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Seizure disorder and/or neurological problem |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Chemical dependency |

No Yes Don't Know

- | | | | |
|-----------------------------|-----------------------------|------------------------------|--|
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Down syndrome |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Prader-Willi syndrome |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Fetal alcohol spectrum disorder (FASD) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Limited or no vision – legally blind |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Hearing loss – severe or profound |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Other disabilities not listed: _____ |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | No other disabilities other than ID (if person has no other disabilities, check 'yes') |

BI-13. What health conditions are noted in this person's record?

CHECK ONE ANSWER FOR EACH ROW. This is very important for data analysis purposes. Check "YES" if the person has the listed condition; check "No" if they do not; check "Don't Know" if information is not available.

No Yes Don't Know

- | | | | |
|-----------------------------|-----------------------------|------------------------------|---|
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Cardiovascular disease (e.g., coronary heart disease, angina) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Diabetes (including Type 1 and Type 2) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Cancer (e.g., breast, prostate, colon, lung, etc.) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | High blood pressure |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | High cholesterol |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Dysphagia (i.e., difficulty swallowing) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Pressure ulcers (bed sores) |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Alzheimer's disease or other dementia |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Oral health or dental problems that cause ongoing pain or difficulty eating |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Sleep apnea |
| <input type="checkbox"/> 1. | <input type="checkbox"/> 2. | <input type="checkbox"/> 99. | Other health conditions not listed: _____ |

BI-14. What is this person's preferred language? (What language does s/he best understand?)

- ☐ 1. English
- ☐ 3. Spanish
- ☐ 4. Mandarin
- ☐ 5. Tagalog
- ☐ 6. Vietnamese
- ☐ 7. Korean
- ☐ 8. Arabic
- ☐ 9. Armenian
- ☐ 10. Farsi

- ☐ 11. Hmong
- ☐ 12. Khmer
- ☐ 13. Laos
- ☐ 14. Russian
- ☐ 15. American Sign Language (ASL)
- ☐ 16. Other (please specify): _____

BI-15. What is this person's preferred means of communication?

Recognizing that more than one means of communication may be used, please select the most frequently used method of communication that the person prefers to use. Check ONE—most frequently used.

- ☐ 1. Spoken
- ☐ 2. Gestures/body language
- ☐ 3. Sign language or finger spelling
- ☐ 4. Communication aid/device
- ☐ 5. Other: _____
- ☐ 99. Don't know

BI-16. How would you describe this person's mobility? Check ONE.

- ☐ 1. Moves self around environment without aids
- ☐ 2. Moves self around environment with aids or uses wheelchair independently
- ☐ 3. Non-ambulatory, always needs assistance to move around environment
- ☐ 99. Don't know

Health

BI-17. Does this person have a primary care doctor or primary care practitioner?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-18. When was his/her last complete annual physical exam? (We're referring to a *routine exam*, not a visit for a specific problem or illness.) Check ONE.

- ☐ 1. In the past year (anytime less than 12 months ago)
- ☐ 2. One year ago or more
- ☐ 99. Don't know

BI-19. When was his/her last oral exam (routine preventative dental care)? Check ONE.

- ☐ 1. Within the last 6 months
- ☐ 2. Within the past year (more than 6 months ago but less than 12 months ago)
- ☐ 3. One year ago or more
- ☐ 99. Don't know

BI-20. When was the last time this person had an eye exam/vision screening?

- ☐ 1. Within the past year (anytime less than 12 months ago)
- ☐ 2. Within the past 2 years (more than 1 year ago but less than 2 years ago)
- ☐ 3. Within the past 3 years (more than 2 years ago but less than 3 years ago)
- ☐ 4. Within the past 5 years (more than 3 years ago but less than 5 years ago)
- ☐ 5. 5 or more years ago
- ☐ 6. Has never had a vision screening
- ☐ 99. Don't know

BI-21. When was the last time this person had a hearing test?

- ☐ 1. Within the past 5 years (anytime less than 5 years ago)
- ☐ 2. 5 years ago or more
- ☐ 3. Has never had a hearing test
- ☐ 99. Don't know

BI-22. During the past 12 months, has this person had a flu vaccination?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

CA-BI.-1 During the past 12 months, has this person had a pneumonia vaccination?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-23. How much does this person weigh? ____ ____ ____ lbs.

BI-24. How tall is this person? ____ Feet ____ ____ Inches

BI-25. Does this person use nicotine or tobacco products (e.g., cigarettes, e-cigarettes, chewing tobacco, etc.)?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-26. If female, when was her last Pap test screening? (A Pap test is used to check women for cancer of the cervix.) Check ONE. Will be reported for females age 21 and over.

- ☐ 98. Not applicable – individual is not female or individual is under age 21
- ☐ 1. Within the past year (anytime less than 12 months ago)
- ☐ 2. Within the past 2 years (more than 1 year ago but less than 2 years ago)
- ☐ 3. Within the past 3 years (more than 2 years ago but less than 3 years ago)
- ☐ 4. Within the past 5 years (more than 3 years ago but less than 5 years ago)
- ☐ 5. 5 or more years ago
- ☐ 6. Has never had a Pap test
- ☐ 99. Don't know

BI-27. If female, when was her last mammogram? (A mammogram is an x-ray of each breast to check for breast cancer.) Check ONE. Will be reported for females age 40 and over.

- ☐ 98. Not applicable – individual is not female or individual is under age 40
- ☐ 1. Within the past year (anytime less than 12 months ago)
- ☐ 2. Within the past 2 years (more than 1 year ago but less than 2 years ago)
- ☐ 3. Within the past 3 years (more than 2 years ago but less than 3 years ago)
- ☐ 4. Within the past 5 years (more than 3 years ago but less than 5 years ago)
- ☐ 5. 5 or more years ago
- ☐ 6. Has never had a mammogram
- ☐ 99. Don't know

BI-28. Has this person received screening for colorectal cancer? Check ALL THAT APPLY. Will be reported for adults age 50 to 74.

- ☐ 98. Not applicable – individual is under age 50 or over age 75
- ☐ 1. Colonoscopy within the past 10 years
- ☐ 2. Flexible sigmoidoscopy within the past 5 years
- ☐ 3. Testing for colorectal cancer with stool sample, using a Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT) in the past year.
- ☐ 4. Has never had screening for colorectal cancer or screening was more than 10 years ago
- ☐ 99. Don't know

BI-29. If this person has a seizure disorder, how often do seizures occur? Check ONE.

- ☐ 98. Not applicable – individual does not have a seizure disorder
- ☐ 1. Seizures are controlled
- ☐ 2. Less frequently than once a month
- ☐ 3. At least once a month, though not once a week
- ☐ 4. At least once a week
- ☐ 99. Don't know

BI-30. Does this person currently take medications to treat mood disorders, anxiety, and/or psychotic disorders?

Medications for mood disorders: Any drug prescribed to elevate or stabilize mood (reduce mood swings) – for example, to treat depression, mania, or bipolar disorder.

Medications for anxiety: Any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.

Medications for psychotic disorders: Any drug (e.g., anti-psychotic or “neuroleptic”) used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.

- ☐ 1. No —> code BI-31 as ‘Not Applicable’
- ☐ 2. Yes
- ☐ 99. Don’t know — code BI-31 as ‘Don’t Know’

BI-31. If yes, how many medications to treat mood disorders, anxiety, and/or psychotic disorders does this person take?

- ☐ 98. Not applicable – does not take medication for these disorders
- ☐ 1. One or two medications
- ☐ 2. Three or four medications
- ☐ 3. Five to ten medications
- ☐ 4. Eleven or more medications
- ☐ 99. Don’t know

BI-32. Does this person currently take medications for behavioral challenges?

Medications for behavioral challenges: Any drug prescribed for a behavior modification purpose (e.g., stimulant, sedative, or beta-blocker to treat ADHD, aggression, self-injurious behavior, etc.).

- ☐ 1. No — code BI-33 as ‘Not Applicable’
- ☐ 2. Yes
- ☐ 99. Don’t know — code BI-33 as ‘Don’t Know’

BI-33. If yes, how many medications to treat behavioral challenges does this person take?

CHECK ONE

- ☐ 98. Not applicable — does not take medication for these disorders
- ☐ 1. One or two medications
- ☐ 2. Three or four medications
- ☐ 3. Five to ten medications
- ☐ 4. Eleven or more medications
- ☐ 99. Don’t know

BI-34. Does this person have a behavior plan?

A behavior plan is based on an assessment of an individual's challenging behavior. The plan includes a description of the individual's strengths, preferences, and interests; goal(s) related to diminishing and/or eliminating the challenging behavior; and applicable information about the nature of the behavior and potential triggering events. The plan should describe the interventions and accommodations that will contribute to the goal(s). It should also include the ways in which progress will be monitored, the staff who will be responsible for the interventions, and the length of time that the plan will be in place.

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

Residence

BI-35. How long has this person lived in his/her current residence?

- ☐ 98. Not applicable — homeless
- ☐ 1. Less than one year
- ☐ 2. One to three years
- ☐ 3. Four to five years
- ☐ 4. Over five years
- ☐ 99. Don't know

BI-36. How would you characterize the place where this person lives? Check ONE. Double check prefilled information is correct.

Intermediate care facility for persons with I/DD (ICF/IID) or other institutional setting

- ☐ 1. ICF/IID, 4-6 residents with disabilities
- ☐ 2. ICF/IID, 7-15 residents with disabilities
- ☐ 3. ICF/IID, 16 or more residents with disabilities
- ☐ 4. Nursing facility
- ☐ 5. Other specialized institutional facility

Group residential setting (e.g., group home).

Group residential settings are owned, operated and/or controlled by a service provider agency.

('Controlled' means the service provider is also connected to the property by lease or ownership. If the person changed their service provider agency, would they need to move? If "YES", as the residence is considered provider owned, operated and/or controlled.)

- ☐ 6. Group living setting, 2-3 people with disabilities
- ☐ 7. Group living setting, 4-6 people with disabilities
- ☐ 8. Group living setting, 7-15 people with disabilities

Own home or apartment.

- ☐ 9. Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s) or spouse
- ☐ 10. Parent/relative's home (may include paid services to family for residential supports)

Foster or host home

- ☐ 11. Foster care or host home (round-the-clock services provided in a single-family residence where two or more people with a disability live with a person or family who furnishes services)
- ☐ 12. Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living)

Other

- ☐ 13. Homeless or crisis bed placement
- ☐ 14. Other (specify): _____
- ☐ 99. Don't know

BI-37. Is the person's residence owned or controlled by a service provider?

('Controlled' means the service provider is also connected to the property by lease or ownership. This includes foster care or host home settings as defined in BI-36.

If the person changed their service provider agency, would they need to move? If they would, respond "YES" to this question, as the residence is considered provider owned or controlled.)

- ☐ 1. No; person owns, rents, or is living with family or friends
- ☐ 2. Yes
- ☐ 99. Don't know
- ☐ 98. Not Applicable — person is homeless

BI-38. If this person lives in a group home, an Intermediate Care Facility for individuals with I/DD (ICF/IID) or specialized institutional facility, is it publicly or privately operated? CHECK ONE.

- ☐ 1. Public (staff are employed by a state or local government entity)
- ☐ 2. Private
- ☐ 99. Don't know
- ☐ 98. Not Applicable — person does not live in a group home, ICF/IID, or specialized institutional facility

BI-39. Is the person named on the lease, deed, or other legally enforceable rental agreement?

- ☐ 1. No
- ☐ 2. Yes, named on lease or deed
- ☐ 3. Yes, named on other legally enforceable rental agreement
- ☐ 99. Don't know

BI-40. Does the person own his or her own home?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-41. Has this person ever lived (longer than a year) in an institutional setting (for example a Developmental Center, nursing home or large ICF)? *This question is asking whether the person has ever lived for at least 12 consecutive months in an institutional setting.*

Check ALL THAT APPLY


- ☐ 1. No
- ☐ 2. State hospital or state developmental center for people with I/DD
- ☐ 3. ICF, private
- ☐ 4. Nursing home
- ☐ 5. Other (such as children's residential settings, psychiatric facility):

- ☐ 99. Don't know

BI-42. What amount of paid support does this person receive at home? (Include any paid support, regardless of funding source.) Check ONE.

- ☐ 1. 24-hour on-site support or supervision (people living with or being available in his/her home during all hours that s/he is home)
- ☐ 2. Daily on-site support (for a limited number of hours/day, not round-the-clock)
- ☐ 3. Scheduled, less frequent than daily support
- ☐ 4. As-needed visitation and phone contact
- ☐ 5. None of the above
- ☐ 99. Don't know

Employment/Other Daily Activities

 **See PS-7.** Please provide data based on a **typical two-week period**.

Type of Activity Definitions: <u>Community-based setting</u> is a place where most people do not have disabilities. <u>Facility-based setting</u> is a place where most people do have disabilities.	a) Does this person do this activity during the typical two-week period ?	If yes: b) Number of hours worked or spent at this activity during the typical two-week period :	c) Wage (not including benefits and before taxes or deductions) earned at this activity during the typical two-week period :	d) Does this person get publicly funded services or supports to participate in this activity?	e) Is the job or activity done primarily by a group of people with disabilities?
BI-43 Paid individual job in a community-based setting <i>A person working at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (e.g., competitive employment).</i>	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	Number of hours for which person is paid in typical two-week period : ____	HOURLY WAGE \$ ____ . ____/hr	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	N/A
BI-44 Paid small-group job in a community-based setting <i>The activity is done in an integrated setting, as part of a group of not more than 8 people with disabilities (e.g., enclave, work crew).</i>	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	Number of hours for which person is paid in typical two-week period : ____	HOURLY WAGE \$ ____ . ____/hr	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	N/A
BI-45 Unpaid activity in a community-based setting <i>(e.g., volunteer activities, skills training, community supports)</i>	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	Number of hours spent at activity in typical two-week period : ____	N/A	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know

<p>BI-46 Paid work in a community business that primarily hires people with disabilities</p> <p><i>In this job, the employees with disabilities interact with the non-disabled population; this job is NOT in a traditional sheltered workshop and is NOT an enclave. Examples include bakeries, carwashes, thrift stores, etc.</i></p>	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	Number of hours for which person is paid in typical two-week period: ____	HOURLY WAGE \$ ____ . ____/hr	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	N/A
<p>BI-47 Paid work performed in a facility-based setting</p> <p><i>(e.g., traditional sheltered workshop or work activity center; the location has been developed specifically to provide work activity exclusively for people with disabilities and people may be paid sub-minimum wage.)</i></p>	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	Number of hours for which person is paid in typical two-week period: ____	TOTAL WAGES EARNED IN TYPICAL TWO WEEK PERIOD \$ ____ . ____	N/A	N/A
<p>BI-48 Unpaid activity in a facility-based setting</p> <p><i>(e.g., day habilitation, seniors programs, drop-in centers)</i></p>	<input type="checkbox"/> 1. No <input type="checkbox"/> 2. Yes <input type="checkbox"/> 99. Don't know	Number of hours spent at activity in typical two-week period: ____	N/A	N/A	N/A

BI-49. Is community employment a goal in this person's individual program plan (IPP)?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-50. Is this person enrolled in school?

- ☐ 1. No
- ☐ 2. Yes, high school
- ☐ 3. Yes, vocational school or certificate program
- ☐ 4. Yes, college
- ☐ 99. Don't know

Community Employment

If BI-43 and/or BI-44 and/or BI-46 above is checked "Yes," please answer BI-51 through BI-54.

BI-51. Does this person receive paid time off (e.g., vacation, holiday, or sick time) at his/her job?

- ☐ 98. Not applicable – no paid job in a community-based setting
- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-52. How long has this person been working at his/her current job? If multiple jobs, pick the job the person has worked at the longest.

___ ___ years and ___ ___ months

BI-53. Is this person self-employed?

- ☐ 98. Not applicable – no paid job in a community-based setting
- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-54. What type of job does this person have? Check all responses that describe work done regularly by the individual. (*List continues on the next page*)

- ☐ 98. Not applicable – no paid job in a community-based setting
- ☐ 1. Food preparation and food service
- ☐ 2. Building and grounds cleaning or maintenance
- ☐ 3. Personal care provider
- ☐ 4. Retail job such as sales clerk or stock person
- ☐ 5. General office and administrative support

- ☐ 6. Farming, fishing, forestry worker
- ☐ 7. Construction or repair occupation
- ☐ 8. Assembly, manufacturing, or packaging
- ☐ 9. Materials handling, mail distribution
- ☐ 10. Management, business, or financial operations
- ☐ 11. Professional or technical occupation
- ☐ 12. Other

Other supports and services

BI-55. Which services/supports funded by the regional center does this person receive? For additional guidance on coding and response options, please refer to the Background Information Guide that was provided by your Quality Assessment Coordinator (QAC).

Check ONE ANSWER FOR EACH ROW.

No	Yes	Don't Know	
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Service coordination/case management
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Respite/family support (<i>a person who cares for the individual to give family or the individual a 'break'. Includes recreational respite care.</i>)
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Transportation (<i>arrangements or provision of transportation, e.g., paratransit</i>)
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Assistance finding, maintaining, or changing jobs (<i>e.g., a job coach, vocational training, on-the-job training, etc.</i>)
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Day services other than employment (<i>e.g., day program or workshop</i>)
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Education, training, or skills development (<i>e.g., school, college, or other training programs</i>)
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Healthcare coordination (<i>help navigating the healthcare system, e.g., finding a doctor who understands unique needs of individual, when to make appointments, with whom, when to take medications, etc.</i>) Note, there is a separate option, below, if the person needs better/different insurance/benefits.
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Oralcare coordination (<i>help navigating the oralcare system, e.g., finding a doctor who understands unique needs of individual, when to make appointments, with whom, when to take medications, etc.</i>) Note, there is a separate option, below, if the person needs better/different insurance/benefits.
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Assistance finding, maintaining, or changing housing (<i>includes help finding a new home or staying in the home, help to be a good tenant</i>)
<input type="checkbox"/> 1.	<input type="checkbox"/> 2.	<input type="checkbox"/> 99.	Help with social/relationship issues, meeting people (<i>help finding friends, or organizations to be a part of</i>)

No Yes Don't Know

☐ 1. ☐ 2. ☐ 99. **Communication technology** (*technology or other assistance to support the person's communication, e.g., communication board, text speak, Dynavox*)
Note, this is not referring to 'standard' communication technology such as a phone or cell phone.

☐ 1. ☐ 2. ☐ 99. **Environmental adaptations/home modifications** (*changes to the home environment to make it easier for the individual with a disability to get around and live in the home, includes remote monitoring technology*)

☐ 1. ☐ 2. ☐ 99. **Benefits/insurance information** (*information on benefits for which the individual might qualify, how to apply, etc.*)

☐ 1. ☐ 2. ☐ 99. **Residential support services** (*this includes a number of supports the person may receive in the home such as homemaker or chore services*)

☐ 1. ☐ 2. ☐ 99. **Other:** _____

BI-56. What is the funding source for supports for this person? (Please obtain this information from a state data system or official record if possible.) Check ALL THAT APPLY.

- ☐ 1. ICF/IID (Intermediate Care Facility for individuals with intellectual disabilities) Funded
- ☐ 2. Medicaid HCBS Waiver-Funded Services
- ☐ 3. Medicaid State Plan Funded Services
- ☐ 4. Exclusively supported by State Funds (no Medicaid services beyond health care)
- ☐ 99. Don't know

BI-57. Does this person currently receive Medicare?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 99. Don't know

BI-58. Is this person currently using a self-directed supports option?

Is this person currently using a self-directed/participant-directed supports option (also known as self-determination) and has a financial management service (also called a fiscal agent, fiscal intermediary, intermediary service organization, etc.)? These options offer individuals (and their representatives) the opportunity to manage some or all of their services. For example, they may hire and fire their own support workers and/or have control over their budget or services.

- ☐ 1. No → Code BI-59 as 'Not Applicable'
- ☐ 2. Yes
- ☐ 99. Don't know – Code BI-59 as 'Don't Know'

BI-59. If yes, who employs this person's support workers?

- ☐ 98. Not Applicable – not using self-directed/participant-directed supports
- ☐ 1. The person (or his/her representative) is the common-law employer. A fiscal intermediary functions as the person's agent to perform payroll and other responsibilities required by law.
- ☐ 2. The person (or his/her representative) is the employer and manages all payroll and other employer responsibilities.
- ☐ 3. An "agency with choice" is the common-law employer of the support workers; selected/recruited by the individual, the agency performs necessary payroll and human resources functions. The person (or his/her representative) is the co-employer (managing employer).
- ☐ 99. Don't know

Behavioral Support Needs

Analyses of project data show that the extent of behavioral support needs is significantly related to many of the questions on the survey. The requested information is used to "adjust" the data to make valid comparisons across states. The responses will not be used to identify any individual.

Questions BI-60 through BI-62 rely on the assessment of someone who knows the individual well. The surveyor may ask a family member or staff person on site to answer these. This information may also be obtained from service coordinators or through record review.

Please identify the level of support the person needs to manage any of the behaviors listed below.

BI-60. Self-injurious behavior

Refers to attempts to cause harm to one's own body; for example, by hitting or biting self, banging head, scratching or puncturing skin, or ingesting inedible substances.

- ☐ 1. No support needed
- ☐ 2. Some support needed; requires only occasional assistance or monitoring
- ☐ 3. Extensive support needed; frequent or severe enough to require regular assistance
- ☐ 99. Don't know

BI-61. Disruptive behavior

Refers to behavior that interferes with the activities of others; for example, by laughing or crying without apparent reason, yelling or screaming, cursing, or threatening.

- ☐ 1. No support needed
- ☐ 2. Some support needed; requires only occasional assistance or monitoring
- ☐ 3. Extensive support needed; frequent or severe enough to require regular assistance
- ☐ 99. Don't know

BI-62 Behavior that is destructive or harmful to others

Refers broadly to externally directed, defiant behavior; for example, taking other people's property, destroying property, stealing, or assaulting/injuring others.

- ☐ 1. No support needed
- ☐ 2. Some support needed; requires only occasional assistance or monitoring
- ☐ 3. Extensive support needed; frequent or severe enough to require regular assistance
- ☐ 99. Don't know

BI-63. Who provided information for Background Information for this survey? Check ALL THAT APPLY.

- ☐ 1. Case Management/Service Coordinator Records
- ☐ 2. Service Provider Records
- ☐ 3. Regional Center Database
- ☐ 4. Medi-Cal Agency Database
- ☐ 5. Individual being surveyed/family member
- ☐ 6. Other: _____

• END OF BACKGROUND INFORMATION SECTION •



Section I: Face-to-Face Survey With Person Receiving Services and Supports

General Instructions

- This section may only be completed by directly surveying the person receiving services and supports.
- Prior to the survey, surveyors should use the Pre-Survey Form to fill in the blanks throughout the survey. Using familiar names and terms during the survey will help ensure that the person understands the questions. Questions that refer to information from the Pre-Survey Form are indicated with a bell: 🔔
- Do not use responses from any other person to complete this section.
- If possible, the survey should be conducted in private. Others may be present if the individual requests, or if another person is needed for interpretation purposes. If staff believe that a private survey may pose a risk to the surveyor, then staff should be present. If others are providing assistance, surveyors should emphasize that we are trying to find out the individual's perspective.
- Be sure to read all instructions carefully.
- Help the person with any words that he/she does not understand. You may repeat or rephrase questions to improve understanding. For some questions, we provide a suggested rephrasing in parentheses—though you don't need to limit yourself to these suggestions.
- Do not read or show the list of response options to the individual. Let them answer in their own words and then code the most appropriate response.
- Individuals may skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as "99".
- If you have any questions concerning the intent of a survey question or need additional help in rephrasing a question, refer to the training materials provided by HSRI.
- A wide margin is provided for recording notes as necessary. Just be sure your response choices are clearly marked.
- Please fill out the **Surveyor Feedback Sheet** after each interview.

First, take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

"Hi, my name is _____. I'm from _____, and I'm here to ask you some questions about where you live, where you work, your friends and family, and the people who help you. By answering these questions,

you are helping us figure out how people in CA are doing, and how to make supports and services better.”

“This is *not* a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer. Whatever answers you give, you will not get into trouble and no one will be mad at you.”

“You don't have to answer any questions that you don't want to. Just tell me if you don't want to answer.”

“I'd like to know your opinions, how you feel about things. Whatever you tell me will be kept private, so you can be honest.”

AGREEMENT TO PARTICIPATE: Did the person indicate to the surveyor that they agree to participate in the NCI survey discussion?

- ☐ 2. Yes
- ☐ 1. No

Home

I'm going to start by asking you some questions about where you live.

1. Do you like your home or where you live? (Do you like living here?)

- ☐ 2. Yes → Code Question 2 as 'Not Applicable'
- ☐ 3. In-between → Ask Question 2
- ☐ 1. No → Ask Question 2
- ☐ 99. Don't know, no response, unclear response → Code Question 2 as 'Don't know, no response, unclear response'

2. If In-between or No: What don't you like about where you live?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable
- ☐ 1. Accessibility
- ☐ 2. Feels unsafe in neighborhood or home
- ☐ 3. Home needs repairs or upkeep
- ☐ 4. It doesn't feel like home
- ☐ 5. Problems with roommates
- ☐ 6. Problems with staff
- ☐ 7. Wants to be closer to family and/or friends
- ☐ 8. Wants more independence
- ☐ 9. Other _____
- ☐ 99. Don't know, no response, unclear response

3. Would you like to live somewhere else?

- ☐ 2. Yes
- ☐ 3. In-between
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

4. Do people let you know before they come into your home? *Do they ring the doorbell or knock first and wait for an answer?*

Do not include people who live in the home. Include staff who have keys (i.e., if they knock, come in only when scheduled or expected.)

- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response, or people do not come into your home

CA-1. Are there staff (or a family member) at your home where you live who speak your preferred language?

- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response, or staff do not come into your home

5. Do people let you know before coming into your bedroom?

- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response, or people do not come into your bedroom

6. Do you have a place to be alone in your home? *Can you have time to yourself?*

- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Employment/Other Daily Activities

Now I'm going to ask about what you do during the day—if you have a paid job or other place that you go to.

7. Do you have a paid job in the community?

A community job refers to paid work – either competitive or supported employment (includes both individual and group employment, such as a work

crew or enclave). It does not include work done in facility-based settings like sheltered workshops. It also does not include volunteer (unpaid) activities.

PS-7



Do you work at _____?

- ☐ 2. Yes – Code Question 8 as ‘Not Applicable’
- ☐ 1. No – Ask Question 8
- ☐ 99. Don’t know, no response, unclear response – Code Questions 8-10 as ‘Don’t know, no response, unclear response’

8. If No, ask: Would you like to have a job in the community?

- ☐ 98. Not Applicable – has job in the community
- ☐ 2. Yes
- ☐ 3. In-between
- ☐ 1. No
- ☐ 99. Don’t know, no response, unclear response

If person does not have a job in the community, code Questions CA-2, CA-3, 9 and 10, below, as ‘Not Applicable’.

CA-2 If over 55 years old, can you stop working if you want to?

- ☐ 98. Not Applicable – no job in the community
- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don’t know, no response, unclear response

PS-7



9. Do you like working there?

Do you like working at _____?

- ☐ 98. Not Applicable – no job in the community
- ☐ 2. Yes
- ☐ 3. In-between
- ☐ 1. No
- ☐ 99. Don’t know, no response, unclear response

10. Would you like to work somewhere else? Would you like a different job instead of this one?

- ☐ 98. Not Applicable – no job in the community
- ☐ 2. Yes
- ☐ 3. In-between
- ☐ 1. No
- ☐ 99. Don’t know, no response, unclear response

CA-3 Are there staff at your job who speak your preferred language?

- ☐ 98. Not Applicable – no job in the community
- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

PS-8



11. Do you go to a day program or sheltered workshop (program or center where other people with disabilities spend their days)?

(Do you go to _____?)

Information for the surveyor: **Day programs** for people with I/DD are typically segregated and may provide socialization, habilitation, prevocational and skills training, social and/or recreational activities.

Sheltered workshops are facility-based day programs where people with I/DD spend their days in a segregated setting to carry out specific tasks (often piece-work).

- ☐ 2. Yes – Ask Questions 12 and CA-4
- ☐ 1. No – Code Questions 12 and CA-4 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response – Code Question 12 and CA-4 as 'Don't know, no response, unclear response'

CA-4 Are there staff at your day program or workshop who speak your preferred language?

- ☐ 98. Not Applicable, does not attend day program or sheltered workshop
- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

12. I'd like to know about the amount of time you spend at the day program or sheltered workshop. We have 4 choices to choose from:

[Interviewer reads options]

- ☐ 98. Not Applicable – does not go to day program or sheltered workshop
- ☐ 2. I would like to spend more time there
- ☐ 3. I am happy with the amount of time I spend there
- ☐ 4. I would like to spend less time there
- ☐ 1. I do not want to spend any time there

- ☐ 99. Don't know, no response, unclear response

13. Do you take classes, training, or do something to help you get a job, get a better job, or do better at the job you have now?

Note to surveyors: We are trying to find out if the person is doing any type of activity to prepare themselves for another job.

- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

14. Do you volunteer?

- ☐ 2. Yes
- ☐ 1. No -> Code CA-5 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response - Code CA-5 as 'Not Applicable'

CA-5 – If yes, do you volunteer at your day or work program?

- ☐ 98. Not Applicable – does not go to day program or sheltered workshop or does not volunteer
- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Feeling Safe

Now I'm going to ask you some personal questions about your safety. Remember, you don't have to answer any questions that you don't want to.

15. Are there any places where you feel afraid or scared?

[You may read list below. Check ALL THAT APPLY.]

- ☐ 1. Home
- ☐ 2. Day program
- ☐ 3. Work
- ☐ 4. Walking in the community
- ☐ 5. In transport (on the bus, van, etc.)
- ☐ 6. Other _____
- ☐ 98. Does not feel afraid anywhere
- ☐ 99. Don't know, no response, unclear response

16. If you ever feel afraid, is there someone you can talk to?

Please ask question to all respondents.

- ☐ 2. Yes
- ☐ 3. Maybe, not sure
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Friends & Family

Now I'm going to ask you about friends and family.

17. Do you have friends you like to talk to or do things with?

If s/he answers "yes", ask who the friends are and try to determine if they are family, staff, roommates, coworkers, etc. You can use prompts such as: *Can you tell me their names? Are these friends staff or your family?*

- ☐ 2. Yes, has friends who are not staff or family
- ☐ 3. Yes, all friends are staff or family, or cannot determine
- ☐ 1. No, does not have friends – code Question 18 as 'No' and Questions 20-22 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response

18. Do you have a best friend, or someone you are really close to? (Is there someone you can talk to about personal things?) *Can include staff or family member.*

- ☐ 2. Yes, has a best friend
- ☐ 1. No, does not have a best friend
- ☐ 99. Don't know, no response, unclear response

19. Do you want more help to make new friends or keep in contact with your friends?

- ☐ 2. Yes
- ☐ 3. Maybe
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

If the person responds "No" to Questions 17-18, code Questions 20-22 as 'Not Applicable'.

20. Can you see your friends when you want to? *Can you meet up with your friends when you want to?*

- ☐ 98. Not Applicable – does not have any friends
- ☐ 2. Yes → Code Question 21 as 'Not Applicable'
- ☐ 3. Sometimes can't see friends (e.g., not enough staff or transportation) → Ask Question 21
- ☐ 1. No, often unable to see friends → Ask Question 21
- ☐ 99. Don't know, no response, unclear response → Code Question 21 as 'Don't know, no response, unclear response'

21. If no, why can't you see your friends when you want to?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – does not have friends or can see friends when s/he wants to (or does not want to)
- ☐ 1. Lack of transportation
- ☐ 2. Lack of support staff
- ☐ 3. Rules or restrictions about seeing friends
- ☐ 4. Money/cost of going out
- ☐ 5. Difficult finding a good time to get together
- ☐ 6. Other: _____
- ☐ 99. Don't know, no response, unclear response

22. Do you have other ways of talking, chatting or communicating with your friends when you cannot see them? *Like over the phone, through email, texting, messaging, etc.?*

- ☐ 98. Not Applicable – does not have friends
- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

23. Can you go on a date if you want to?

- ☐ 98. Not Applicable – does not want to date
- ☐ 2. Yes, can date or is married or living with partner
- ☐ 3. Yes, but there are some restrictions or rules about dating
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

24. Do you ever feel lonely? Do you ever feel like you don't have anyone to talk to?

[If s/he responds "yes," probe to determine how often s/he feels lonely.]

- ☐ 2. Yes, often
- ☐ 3. Sometimes
- ☐ 1. No, not often
- ☐ 99. Don't know, no response, unclear response

25. Can you see and/or communicate with your family when you want to? Can you pick the times you see them? Does someone help you make plans to see them?

If family is not available or doesn't wish to have contact, code as '98 Not Applicable'. If the person has family but doesn't want to see them, code as '2 Yes, sees family whenever s/he wants to, or chooses not to see family'.

- ☐ 98. Not Applicable – lives with family, family not available, person doesn't have family, or family doesn't have contact
- ☐ 2. Yes, sees family whenever s/he wants to, or chooses not to see family
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Community Participation & Leisure

Now I'm going to ask you about the things you like to do when you go out. What kinds of things do you like to do when you go out?

[Response is not being collected. This question helps identify the types of things the person likes to do in the community. In Questions 26 and 27, the surveyor can replace 'the things you like to do' phrase with the specific activities the person identifies.]

26. Are you able to go out and do the things you like to do?

- ☐ 98. Not Applicable – doesn't name things s/he likes to do
- ☐ 2. Yes, I can go out and do the things I like to do.
- ☐ 3. In between. I go out and do some things that I like, but there are things I like to do that I can't do.
- ☐ 1. No, I don't get to do any of the things I like to do → code Question 27 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response → Code Question 27 as 'Don't know, no response, unclear response'

27. Do you get to do the things you like to do as much as you want to?

- ☐ 98. Not Applicable – doesn't name things s/he likes to do, isn't able to do the things s/he likes to do.
- ☐ 2. Yes, I do the things I like to do as much as I like.
- ☐ 1. No, I do go out and do some things that I like, but I'd like to do more.
- ☐ 99. Don't know, no response, unclear response

28. When you are at home, do you have enough things you like to do? Do you have things to do so you are not bored at home?

This can include hobbies or other leisure activities that the person finds enjoyable.

- ☐ 2. Yes, enough
- ☐ 3. In the middle – sometimes I have enough, sometimes I want to do something else at home.
- ☐ 1. Not enough
- ☐ 99. Don't know, no response, unclear response

Rights & Privacy

29. Do people read your mail or email without asking you first?

- ☐ 98. Not Applicable – does not get mail/email
- ☐ 2. Yes, mail/email is read without permission
- ☐ 1. No, person reads own mail/email or others read with permission
- ☐ 99. Don't know, no response, unclear response

30. Can you be alone with friends or visitors at your home?

- ☐ 98. Not Applicable – no friends or visitors, or no friends visit your home – code Question 31 as "Not Applicable"
- ☐ 2. Yes, can be alone with friends or visitors
- ☐ 1. No, there are rules against being alone with friends or visitors
- ☐ 99. Don't know, no response, unclear response

31. Are there rules about having friends or visitors in your home?

- ☐ 98. Not Applicable – no friends or visitors, or no friends visit the home
- ☐ 1. No rules about having friends or visitors in the home
- ☐ 2. There are rules against having friends or visitors in the home (e.g., times that are okay, certain friends but not others..., rules about privacy)
- ☐ 99. Don't know, no response, unclear response

32. Can you use the phone and internet when you want to?

- ☐ 98. Not Applicable – doesn't have access or unable to use phone/internet
- ☐ 1. No, there are rules/restrictions on use
- ☐ 2. Yes, can use anytime, either independently or with assistance
- ☐ 99. Don't know, no response, unclear response

Satisfaction With Services/Supports

Now I'm going to ask you some questions about your services.

Ask Questions 33 -35 ONLY if the person has a case manager/service coordinator. If the person does not have a case manager/service coordinator → code as 'Not Applicable'.

PS-2



33. Have you met or spoken with your case manager/service coordinator?

(Have you met _____?)

- ☐ 98. Not Applicable – doesn't have case manager/service coordinator – code Question 34 and Question 35 as 'Not Applicable'
- ☐ 2. Yes, person has met or spoken with case manager/service coordinator
- ☐ 3. Maybe, not sure
- ☐ 1. No, person has not met or spoken with case manager/service coordinator
- ☐ 99. Don't know, no response, unclear response

PS-2



34. Does your case manager/service coordinator ask what you want? Does your case manager/service coordinator ask what is important to you?

(Does _____ ask what you want?)

- ☐ 98. Not Applicable – doesn't have case manager/service coordinator, or person doesn't communicate with case manager/service coordinator
- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

35. Are you able to contact your case manager/service coordinator when you want to? Can you talk to your case manager/service coordinator when you want to?

This can include the person's preferred form of communication including messaging.

- ☐ 98. Not Applicable – doesn't have case manager/service coordinator or doesn't contact case manager/service coordinator
- ☐ 2. Yes
- ☐ 3. Sometimes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

36. Do you have an individual program plan (IPP)? Do you have a list of services your case manager/service coordinator will help you get?

- ☐ 2. Yes
- ☐ 3. Maybe, not sure
- ☐ 1. No → code Questions CA-6 and 37-40 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response → Code Questions 37-40 and CA-6 as Don't know, no response, unclear response

CA-6 Did you get a copy of your IPP in your preferred language?

- ☐ 98. Not Applicable –no IPP
- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Usually, people's services get reviewed or looked over once a year. This usually happens at an individual program plan (IPP) meeting with your case manager/service coordinator.

37. Did you take part in the last IPP meeting?

- ☐ 98. Not Applicable – No IPP → code Question 38 as 'Not Applicable'
- ☐ 2. Yes
- ☐ 3. Had the option but chose not to → code Question 38 as 'Not Applicable'
- ☐ 1. No – code Question 38 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response → Code Question 38 as 'Don't know, no response, unclear response'

38. At the IPP meeting, did you know what was being talked about? Did they use words you understood? Did they have the meeting in your preferred language?

- ☐ 98. Not Applicable – did not take part in the meeting or no IPP
- ☐ 2. Yes
- ☐ 3. In between
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

39. Did the IPP meeting include the people you wanted to be there?

- ☐ 98. Not Applicable – no IPP or didn't want specific people at the meeting
- ☐ 2. Yes
- ☐ 3. In between
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

40. Were you able to choose the services that you get as part of your IPP?

- ☐ 98. Not Applicable – no IPP
- ☐ 2. Yes
- ☐ 3. Had some input
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

PS-6


41. Do you have staff who help you? For example, at your home, job, or day program?

Does _____ help you?

- ☐ 2. Yes
- ☐ 1. No → code Questions 42, 43, and CA-7 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response → Code Questions 42 and 43 and CA-7 as 'Don't know, no response, unclear response'

PS-6


42. Do your staff treat you with respect? Do they listen and talk to you?

(Does _____ treat you with respect?)

- ☐ 98. Not Applicable – doesn't have staff
- ☐ 2. Yes – all staff, always
- ☐ 3. Sometimes or some staff
- ☐ 1. No

- ☐ 99. Don't know, no response, unclear response

PS-6



CA-7 Do your staff support you in a way that is respectful to your culture?

- ☐ 98. Not Applicable – doesn't have staff. Code Question 43 as 'Not Applicable'
- ☐ 2. Yes – all staff, always
- ☐ 3. Sometimes or some staff
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

43. Do your staff come and leave when they are supposed to? Do they show up on time? Do they show up when they say they will? Do they leave when they are supposed to?

(Does _____ come and leave when they are supposed to?)

- ☐ 98. Not Applicable – doesn't have staff
- ☐ 2. Yes
- ☐ 3. Maybe, not sure
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Now I'm going to ask you a couple of questions about how you get around.

44. Do you have a way to get places you need to go (like work, appointments, etc.)? Can you get a ride when you need one?

- ☐ 2. Yes, almost always
- ☐ 3. Sometimes
- ☐ 1. No, almost never
- ☐ 99. Don't know, no response, unclear response

45. Are you able to get places when you want to do something outside your home, like going out to see friends, for entertainment, or to do something fun? Can you get a ride when you want one?

- ☐ 2. Yes, almost always
- ☐ 3. Sometimes
- ☐ 1. No, almost never
- ☐ 99. Don't know, no response, unclear response

46. Are services and supports helping you to live a good life?

- ☐ 2. Yes
- ☐ 3. In between
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

FOR THE SURVEYOR

47. SURVEYOR, in your opinion, did the individual appear to understand questions that were answered, and did they answer in a consistent manner? (Do you feel his/her responses were valid?)

Of the questions that were answered for Section I, did you feel the person understood the questions and was able to respond? *Reminder – if responses were unclear they should be coded as '99'*

- ☐ 2. Yes, seemed to give consistent and valid responses to the questions that were answered.
- ☐ 1. No, did not seem to give consistent and valid responses.

If you answered 'Yes' to Question 47, then determine now if the individual is willing to answer more questions. If the individual is not willing to continue, or if you believe comprehension or consistency was a problem and the person does not have a proxy respondent, then say:

"Thank you for your help. It's been very nice talking to you. You've been very helpful."

If the person is willing to continue or has a proxy respondent available, please continue to Section II.

• END OF SECTION I •



Section II: Survey With Person Receiving Services or with Proxy Respondents

Please review Section I, Question 47. Please make sure you have answered that question before proceeding.

General Instructions:

- If at all possible, ask the person receiving services these Section II questions. If the person is unwilling or unable to complete this section, other respondents may be surveyed (family, advocate, staff—but not the case manager or service coordinator). If the individual did not complete Section I or if you believe that s/he did not understand the questions and/or did not answer consistently, do not ask the individual the Section II questions—only ask the proxy respondent(s). Proxy respondents must be knowledgeable in the areas below (they should know the person well and have frequent contact with him/her). Use the alternate wording provided when questioning proxy respondents (e.g., “Did this person...?”).
- For all questions, indicate who the respondent was; please check only one respondent for each question.
- If both the individual and the proxy respondent contributed to the answer, and there is agreement between the two, check “individual” as the respondent.
- If there is disagreement between the individual and the proxy respondent, you may need to ask follow-up questions to determine the most valid response.

Ask the person if s/he wishes to continue with the questions, or if s/he would like to take a short break.

Community Inclusion

In this section, we are trying to find out if the person participates in integrated community activities (activities that include people with and without disabilities). If the individual indicates they have only participated in a non-integrated activity (where only people with disabilities are participating) in the past month, then you should check 'no' as the response. If the person answers 'yes,' you may ask for an example to verify that the person understood the question and that the activity was indeed integrated.

48. How many times did you go shopping in the past month? Examples: groceries, clothing

Other respondent: *In the past month, how many times did this person go shopping?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 1. Did not go shopping – Code Question 49 as 'Not Applicable'
- ☐ 2. One or two times
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don't know, no response, unclear response – Code Question 49 as 'Don't know, no response, unclear response'

49. Who did you usually go shopping with?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn't go out for shopping
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don't know, no response, unclear response

50. How many times did you go out on errands or appointments in the past month?

Examples: bank, post office, hairdressers or barber.

Other respondent: *In the past month, how many times did this person go out on errands or appointments?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 1. Did not go on errands/appointments – Code Question 51 as ‘Not Applicable’
- ☐ 2. One or two times
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don’t know, no response, unclear response – Code Question 51 as ‘Don’t know, no response, unclear response’

51. Who did you usually go with when you went on errands or appointments?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn’t go out for errands or appointments
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don’t know, no response, unclear response

52. Do you participate as a member of community groups in your community? This includes church groups, book clubs, knitting groups or any other formal or informal community group in an inclusive setting.

Other respondent: *Does this person participate in community groups or other activities in the community?*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 2. Yes
- ☐ 1. No – Code Question 53 as ‘Not Applicable’
- ☐ 99. Don’t know, no response, unclear response – Code Question 53 as ‘Don’t know, no response, unclear response’

53. Who did you participate in community groups with?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn't participate in community groups
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don't know, no response, unclear response

54. How many times did you go out for entertainment in the past month? Examples: go to the movies or attend plays, concerts, sporting events, going out dancing.

Other respondent: *In the past month, how many times did this person go out for entertainment?*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 1. Did not go out for entertainment – Code Question 55 as 'Not Applicable'
- ☐ 2. One or two times
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don't know, no response, unclear response – Code Question 55 as 'Don't know, no response, unclear response'

55. Who did you usually go with when you went out for entertainment?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn't go out for entertainment
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don't know, no response, unclear response

56. How many times did you go to a restaurant or coffee shop in the past month?

Other respondent: *In the past month, how many times did this person go out to a restaurant or coffee shop?*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 1. Did not go out to eat – Code Question 57 as ‘Not Applicable’
- ☐ 2. One or two times
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don’t know, no response, unclear response – Code Question 57 as ‘Don’t know, no response, unclear response’

57. Who did you usually go with when you went to restaurants or coffee shops?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn’t go out to eat
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don’t know, no response, unclear response

58. How many times did you go out to a religious service or spiritual practice in the past month? Examples: church, synagogue, study, or other place of worship

Other respondent: In the past month, how many times did this person go out to a religious service or spiritual practice?

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 1. Did not go out for religious/spiritual practice – Code Question 59 and CA-8 as ‘Not Applicable’
- ☐ 2. One or two times
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don’t know, no response, unclear response – Code Question 59 and CA-8 as ‘Don’t know, no response, unclear response’

CA-8 If you did go out for religious or spiritual practice, did you choose the religious service or spiritual practice you went to?

- ☐ 98. Not Applicable – person didn't go out for religious/spiritual practice
- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

59. Who did you usually go with to religious/spiritual practices?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn't go out for religious/spiritual practice
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don't know, no response, unclear response

60. In the past year, did you go away on vacation?

Other respondent: *In the past year, did this person go away on vacation?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 2. Yes
- ☐ 1. No – Code Question 61 as 'Not Applicable'
- ☐ 99. Don't know, no response, unclear response – Code Question 61 as 'Don't know, no response, unclear response'

61. Who did you usually go on vacation with?

Check ALL THAT APPLY.

- ☐ 98. Not Applicable – person didn't go on vacation in the past year
- ☐ 1. Alone
- ☐ 2. Friends
- ☐ 3. Family
- ☐ 4. Housemates or coworkers
- ☐ 5. Staff
- ☐ 6. Others not listed
- ☐ 99. Don't know, no response, unclear response

Choices

The intent of the next set of questions is to determine the extent to which the people receiving services are involved in decision-making.

Instructions

- Code as '2' – If this person played a major role in making the decision. The person may have consulted with others but ultimately made the decision for him/herself.
- Code as '3' – If the person had some input in making the decision but did not play a major role.
- Code as '1' – If the person did not have any input in making the decision.

Choices made with spouses/partners should be coded as '2—person made the choice'.

Do not overuse the 'Not Applicable' code here: It is not appropriate to use '98' to indicate NOT ALLOWED or NOT CAPABLE of making decisions in this area. For those cases, code as '1'.

Read one of the following introductions to the respondent(s):

For Individuals: "I'm going to ask some questions now about some decisions you may have made or helped make. For each question, I'd like you to tell me if you made the choice yourself, if you had some say about it, or if someone else decided for you."

For Proxy Respondents: "I'm going to ask some questions now about decisions this person may have made. For each question, please indicate if s/he made the decision, if s/he had some input in making the decision, or if someone else made the decision for him/her."

62. Who chose (or picked) the place where you live? Did you help pick the place where you live?

Other respondent: *Who chose the place where s/he lives? Did s/he have any input in making the decision?*

If the person lives in their family home, code as '98 - Not Applicable'.

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – person lives in the family home -- Code Question 63 as 'Not Applicable'
- ☐ 2. Person made the choice
- ☐ 3. Person had some input
- ☐ 1. Someone else chose
- ☐ 99. Don't know, no response, unclear response

63. Did you choose (or pick) the people you live with (or did you choose to live by yourself)? Did anyone ask who you'd like to live with? Were you given choices? Did you get to interview people?

PS-5


(Did you choose to live with _____?)

Other respondent: *Did this person choose any of the people s/he lives with? Or: Did this person choose to live alone?*

If the person lives in their family home, please code as **'98 – Not Applicable'**

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – person lives in the family home
- ☐ 2. Person made the choice
- ☐ 3. Person had some input
- ☐ 1. Someone else chose
- ☐ 99. Don't know, no response, unclear response

64. Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

Other respondent: *Who decides this person's daily schedule—like when to get up, when to eat, when to go to sleep?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 2. Person decides
- ☐ 3. Person has help deciding
- ☐ 1. Someone else decides
- ☐ 99. Don't know, no response, unclear response

65. Who decides how you spend your free time (when you are not working, in school, or at the day program)?

Other respondent: *Who decides how this person spends his/her free time?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 2. Person decides
- ☐ 3. Person has help deciding
- ☐ 1. Someone else decides
- ☐ 99. Don't know, no response, unclear response

Question 66, below, refers to choices made concerning paid work in the community.

PS-7


66. Who chose (or picked) the place you work? Did you help make the choice?

Did you choose to work at _____?

Other respondent: *Who chose the place where s/he works? Did s/he have any input in making the decision?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – no job in the community
- ☐ 2. Person made the choice
- ☐ 3. Person had help making the choice
- ☐ 1. Someone else made the choice
- ☐ 99. Don't know, no response, unclear response

Question 67 refers to choices made concerning day programs or other regularly scheduled activities during the day. This does not include paid work in the community.

67. Who chose (or picked) your day program or workshop? Did you help make the choice?

Did you choose to go to _____?

Other respondent: *Who chose the place where s/he goes during the day? Did s/he have any input in making the decision?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – no day program or workshop
- ☐ 2. Person made the choice
- ☐ 3. Person had some input
- ☐ 1. Someone else chose
- ☐ 99. Don't know, no response, unclear response

68. Do you choose what you buy with your spending money? Do not include things like rent or groceries.

Other respondent: *Does this person choose how to spend his/her money?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 2. Person chooses
- ☐ 3. Person has help choosing what to buy, or has set limits (such as can buy small items, but not big items)
- ☐ 1. Someone else chooses
- ☐ 99. Don't know, no response, unclear response

69. Can you change your case manager/service coordinator if you want to?

Can you change _____ if you want to?

Other respondent: *Can this person change his/her case manager/service coordinator if desired?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

PS-8


PS-2


- ☐ 98. Not Applicable – no case manager/service coordinator
- ☐ 2. Yes
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

70. Do you choose (or pick) your staff? Do you get to interview them? Did you get to meet different people or was someone assigned to you? Could you ask to change to someone different?

PS-6



Did you choose _____ to work with you?

Other respondent: *Does this person choose his/her staff?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – no staff
- ☐ 2. Person chose staff
- ☐ 3. Staff are assigned but can be changed if requested by person
- ☐ 1. Someone else chose
- ☐ 99. Don't know, no response, unclear response

Rights

71. Do you have a key to your home?

Other Respondent: *Does this person have a key to his/her home?*

If a person is physically unable to use a key, this question may be marked 'yes' only if the person always has someone (staff, family, friend) available to use the key.

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 2. Yes
- ☐ 3. Maybe, not sure
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

72. Can you lock your bedroom if you want to?

Other respondent: *Can this person lock his/her bedroom if he/she wants to?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – Lives alone
- ☐ 2. Yes
- ☐ 3. Maybe, not sure
- ☐ 1. No

- ☐ 99. Don't know, no response, unclear response

73. Have you ever participated in a self-advocacy group meeting, conference, or event? A self-advocacy group is where people with disabilities meet together to talk about things in their lives that are important to them. Some groups include People First, Speaking for Ourselves, and Self-Advocates Becoming Empowered – SABE.

Do not include human rights groups sponsored by provider agencies.

Have you ever gone to a _____ meeting or event?

Other respondent: Has this person ever attended a self-advocacy group meeting or event?

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – no self-advocacy group in the area
- ☐ 2. Yes
- ☐ 3. Had the opportunity but chose not to participate
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

74. Have you ever voted in a local, state, or federal election?

Other respondent: *Has this person ever voted in a local, state or federal election?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 2. Yes
- ☐ 3. Had the opportunity to register or vote but chose not to
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response

Access to Needed Services/Supports

75. Do you need any of these additional services? Please note type of service or support below.

Other Respondent: *Does this person need any of these additional services?*

For additional information and examples for these responses, please refer to the Interviewer Training Guide that can be provided by your state coordinator.

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

[Please read each item in this list. *List continues on the next page.*] Check ALL THAT APPLY.

- ☐ 98. **NA – Does not need additional services**
- ☐ 1. **Service coordination/case management**

- ☐ 2. **Respite/family support** (*a person who cares for the individual to give family and the individual a 'break'; includes recreational respite care*)
- ☐ 3. **Transportation** (*arrangements or provision of transportation, e.g., paratransit*)
- ☐ 4. **Assistance finding, maintaining, or changing jobs** (*e.g., a job coach, vocational training, on-the-job training, etc.*)
- ☐ 5. **Day services other than employment** (*e.g., day program or workshop*)
- ☐ 6. **Education, training, or skills development** (*e.g., school, college, or other training programs*)
- ☐ 7. **Healthcare coordination** (*help navigating the healthcare system, e.g., finding a doctor who understands unique needs of individual, when to make appointments, with whom, when to take medications, etc.*) Note, there is a separate option if the person needs better/different insurance/benefits.
- ☐ 8. **Oral care coordination** (*help navigating the dental care system, e.g., finding a dentist who understands unique needs of individual, when to make appointments, with whom, when to take medications, etc.*) Note, there is a separate option if the person needs better/different insurance/benefits.
- ☐ 9. **Assistance finding, maintaining, or changing housing** (*includes help finding a new home or staying in the home, help to be a good tenant*)
- ☐ 10. **Residential support services** (*this includes a number of supports the person may receive in the home such as homemaker or chore services*)
- ☐ 11. **Assistance with social/relationship issues, meeting people** (*help finding friends or organizations to be a part of*)
- ☐ 12. **Communication technology** (*technology or other assistance to support the person's communication – e.g., communication board, text speak, Dynavox*) Note, this is not referring to 'standard' communication technology such as a phone or cell phone. (continued on next page)
- ☐ 13. **Environmental adaptations/home modifications** (*changes to the home environment to make it easier for the person to get around and live in the home, includes remote monitoring/call technology*)
- ☐ 14. **Benefits/insurance information** (*information on benefits for which the individual might qualify, how to apply, etc.*)
- ☐ 15. **Other** _____

76. Do you feel that your staff have the right training to meet your needs?

Other respondent: *Does this person's support staff have the right training to meet his/her needs?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 98. Not Applicable – person does not have support staff

- ☐ 2. Yes
- ☐ 3. Maybe, not sure, or only some staff have the right training
- ☐ 1. No
- ☐ 99. Don't know, no response, unclear response, or respondent is staff

Health and Wellness

77. Overall, how would you describe your health?

Other respondent: *Overall, how would you describe this person's health?*

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 1. Excellent
- ☐ 2. Very good
- ☐ 3. Fairly good
- ☐ 4. Poor
- ☐ 99. Don't know, no response, unclear response

78. How many times per week do you do moderate physical activity or exercise in which you are active for at least 10 minutes at a time? For example, how often do you go running, fast walking, dancing, biking, swimming and/or play basketball for at least 10 minutes at a time?

Other respondent: *How many times per week does this person do sports, exercise or physical activity for at least 10 minutes?*

(Moderate physical activity is an activity that causes some increase in breathing or heart rate. Examples include but are not limited to brisk walking, swimming, bicycling)

Check ONE.

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 1. None
- ☐ 2. One or two times (*continued on next page*)
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don't know, no response, unclear response

79. How many times per week do you do physical activity or exercise that makes the muscles in your arms, legs, back, and/or chest work hard – like lifting weights, push-ups, sit-ups, manual labor, physical therapy, etc.?

Other respondent: *How many times per week does this person do physical activity designed to work his/her muscles?*

Check ONE.

Respondent: () 1-Individual () 2-Family/friend () 3-Staff () 4-Other

- ☐ 1. None

- ☐ 2. One or two times
- ☐ 3. Three or four times
- ☐ 4. Five or more times
- ☐ 99. Don't know, no response, unclear response

89. Surveyor: Please indicate all respondents to Section II.

Check ALL THAT APPLY.

- ☐ 1. Person receiving services
- ☐ 2. Advocate, Parent, Guardian/Conservator, Personal Representative, Relative, Friend
- ☐ 3. Staff who provides supports where person lives
- ☐ 4. Staff who provides supports at a day or other service location
- ☐ 5. Other

• END OF SECTION II •



Surveyor Feedback Sheet

Instructions

Please take a few minutes to complete a feedback sheet after each survey.

Please DO NOT INCLUDE any personally identifying information regarding yourself or the individual surveyed (e.g., names, addresses, phone numbers, etc.).

Surveyor's Initials or Code (optional) _____

1. How long did it take to complete the direct face-to-face survey(s) (Sections I and II only)?

___ ___ hours ___ ___ minutes

2. How long did it take to complete the entire form, including making phone calls, collecting background information, arranging and conducting the face-to-face survey, travel time, etc.?

___ ___ hours ___ ___ minutes

3. Were there any questions that were problematic?

___ Yes ___ No

If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement. Remember: Please DO NOT INCLUDE any personally identifying information regarding yourself or the individual surveyed.

Question	Problem/Suggestions
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Other Comments:

Additional Questions for Surveyor(s):

I-1 SURVEYOR, in what language was the survey conducted?

- ☐ 1. English
- ☐ 2. Spanish
- ☐ 3. Mandarin
- ☐ 4. Tagalog
- ☐ 5. Vietnamese
- ☐ 6. Korean
- ☐ 7. Arabic
- ☐ 8. Armenian
- ☐ 9. Farsi
- ☐ 10. Hmong
- ☐ 11. Khmer
- ☐ 12. Laos
- ☐ 13. Russian
- ☐ 14. American Sign Language (ASL)
- ☐ 0. Other _____

I-2 Where was the face-to-face survey held?

Check ALL THAT APPLY.

- ☐ 1. Person's home
- ☐ 2. Person's workplace
- ☐ 3. Provider agency (e.g., provider agency office; not a home or workplace)
- ☐ 4. Public place
- ☐ 5. Other: _____

I-3 What is your job title/relationship to the state agency (or county agency if applicable)?

If there is more than one surveyor, check ALL THAT APPLY. If a surveyor has more than one role, select the principal role for the state agency.

- ☐ 1. Quality assurance staff
- ☐ 2. Case manager/service coordinator
- ☐ 3. Contractor or consultant
- ☐ 4. Person receiving services/self-advocate
- ☐ 5. Parent/family member/guardian of a person receiving services
- ☐ 6. Student
- ☐ 7. Interested citizen (not a family member or provider)
- ☐ 8. Other: _____

I-4 Did you know/had you met the individual prior to conducting this survey?

- ☐ 1. No
- ☐ 2. Yes
- ☐ 3. Not sure

I-5 How many surveyors conducted the survey with this person? (This includes 'shadow surveyors' or other silent observers. This does not include translators.)

- ☐ 1. One
- ☐ 2. Two
- ☐ 3. Three
- ☐ 4. Four or more

I-6 Date of face-to-face survey: (mm/dd/yyyy) ____/____/____

I-7 How was this survey administered?

Check ALL THAT APPLY.

- ☐ 1. Paper
- ☐ 2. Wi-fi connected device
- ☐ 3. Other: _____

I-8 If the person responded to all or part of the survey, how did he/she communicate with the surveyor?

- ☐ 1. Person answered independently
- ☐ 2. Person answered with some verbal assistance
- ☐ 3. Person answered using alternate/picture response format

• END OF ADULT SURVEY •